# Possibly Impossible Patients: Management of Difficult Behavior in Oncology Outpatients

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## **Abstract**

Angry, threatening, or otherwise disruptive behavior by patients can interfere with necessary oncologic treatment, sometimes to the point of rendering continued care impossible. We offer oncology clinicians guidance in dealing with difficult outpatients by discussing the differential diagnosis and multidisciplinary management of treatment-disrupting behavior in the ambulatory oncology setting.

We review the existing literature on dealing with difficult patients and present clinical experience at a comprehensive cancer center where a formalized, institutional process for responding to disruptive outpatients has been developed.

A structured, multidisciplinary approach to deal with difficult behavior in oncology outpatients can improve care and staff morale. Staff using this approach can identify causes of treatment-disrupting behavior, develop and implement appropriate behavior plans, facilitate communication, address mental health issues, and ensure that decisions to terminate a relationship with a patient are ethical, clinically justified, and supported by due process.

In the future, clinical recommendations and institutional guidelines for dealing with difficult patients should be evaluated with more structured, quantitative research.

### Introduction

Existing literature does not adequately describe the challenge of managing disruptive oncology outpatients. Although mental health clinicians receive formal training in dealing with behavioral problems, other staff who also play key roles in managing difficult patients frequently feel a need for more institutional guidance. We summarize key principles, in the absence of a defined standard of care, that we have found useful for managing possibly impossible patients at one comprehensive cancer center.

Psychiatric literature describes personality-based responses to the stress of illness<sup>1-5</sup> and how to help medical staff work with patients in ways that fit their personalities.<sup>6,7</sup> It also sets forth methods—such as setting limits on disruptive behavior and using team meetings to prevent "splitting" (ie, seeing staff as all good or all bad)—for dealing with borderline and other personality disorders in the inpatient setting.<sup>8-10</sup> Although the literature has begun to extend these principles to the ambulatory setting,<sup>11</sup> it does not sufficiently describe the sometimes complex role relationships of clinical, legal, risk management, and patient relations staff who are on outpatient multidisciplinary teams, or the ethical and clinical complexities of terminating treatment relationships in the ambulatory setting when other options have been exhausted.<sup>12-14</sup>

Disruptive patients can be particularly challenging to a cancer center for reasons related to clinicians, patients, and the culture of the institution. Oncology clinicians, who are accustomed to cancer-related distress, value being able to respond sympathetically to their patients' distress. In the ambulatory setting, in which most care takes place, they often allow dissatisfied patients to change providers and to avoid psychiatric consultation. They may be unsure of how to proceed if a difficult patient refuses a mental health referral.

Some patients mistake the mission of a cancer center to extend expert and compassionate care (which is competitively

marketed at times) as support for unrealistic goals and agendas. They may also take encouragement to advocate for themselves as permission to report complaints to clinic authorities. In turn, institutional responses to such complaints can restrict clinicians' usual freedom to set necessary limits on inappropriate behavior.

Several principles have proven useful in responding effectively to patients who are disruptive, threatening, or uncooperative (Table 1). The first is to focus on problem behaviors in a nonpunitive fashion. For example, instead of avoiding or blaming a difficult patient, a team can designate a representative to discuss the importance of mutual respect with the patient, to elicit his or her perspective on difficulties that have arisen in working with staff, and to express the team's desire to overcome these difficulties to provide optimal care. Our institution has found it helpful to codify in policy a list of prohibited aggressive or threatening behaviors (Table 2).

A second principle is to introduce mental health consultation early in the treatment process before disruptive behaviors have alienated the medical team. As part of the team's discussion of a patient's difficult behavior, a consulting psychiatrist or other mental health professional can encourage expression of clinicians' feelings, focus the team's attention on a differential diagnosis of the problem, and discuss possible ways of obtaining an adequate mental health assessment. The oncology team then has several options. The team can present a mental health assessment as a benefit available to the patient who is clearly in distress, as a help to the team in understanding how best to meet the patient's needs, or as an expectation (even, in certain situations, as a condition of continued care).

A third principle is to use regular staff meetings to educate members of the medical team about personality and other psychiatric disorders of patients. This helps to achieve agreement on appropriate expectations and to ventilate negative feelings so

Table 1. Principles for Responding to Disruptive Behavior

#### Principle

Focus on problem behaviors in a nonpunitive fashion

Introduce mental health consultation early in the treatment process

Use regular staff meetings to educate members of the medical team

Assess the patient's potential dangerousness and its probable cause

Design a thoughtful, individualized response to the patient's behavior

Set realistic behavioral expectations and follow through consistently on their implementation with adequate institutional support

Table 2. Examples of Prohibited Conduct

#### **Prohibited Conduct**

Acts of physical aggression (eg, an assault or attempted assault on another person)

Use or possession of explosives, firearms, or other weapons

Intentional damaging of institute property or the property of other patients, family members, or staff

Threats (defined as words or actions that create either reasonable fear in another person or a reasonable perception of intent to harm a person or property or that result in harm or similar consequences); can occur through face-to-face, written, telephone, e-mail, or other (eg, Internet blod) encounters

Comments (even if joking) about violence or possession of weapons

Comments, acts, personal insults, slurs, or the like that a reasonable person would view as demeaning, disparaging, degrading, harassing, or intimidating

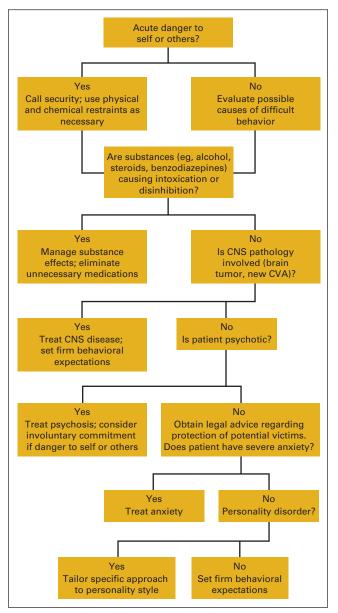
Repeated shouting or rudeness (eg, hanging up on the phone, swearing, paging clinicians unnecessarily at all hours)

Persistent unwelcome attention bestowed on a staff member (eg, unnecessary phone calls, gifts, invitations to dates) after the staff member has requested that the individual cease the unwelcome behavior

that they do not lead to avoiding or inappropriately retaliating against the patient. Team members can share strategies they have found useful to help others modify their approaches.

A fourth principle is to assess the patient's potential dangerousness and probable cause and then to design a thoughtful, individualized response to the patient's behavior. Even when the patient declines formal psychiatric assessment, a mental health professional can assist other team members in thinking through these questions on the basis of their own observations and in deciding whether to insist on an evaluation or involuntary hospitalization. Figure 1 outlines an approach to immediate intervention on the basis of the urgency of the situation and the patient's capacity to comply with treatment expectations for patients with the most commonly responsible diagnoses—psychosis, sociopathy, organic disinhibition or intoxication, severe anxiety (eg, post-traumatic stress disorder [PTSD]), and personality disorder. The cases we describe provide examples of each.

Finally, the team needs to set realistic behavioral expectations and follow through consistently on implementation with adequate institutional support. Several systemic elements, which may vary according to institution, are important for accomplishing this step. For example, our hospital's Department of Patient and Family Relations, which is staffed by patient advocates who are experienced in handling complaints about care, organizes multidisciplinary team meetings, keeps notes,



**Figure 1.** Diagram depicting an approach to immediate intervention. CVA, cerebrovascular accident.

and composes letters that include expectations addressing problematic behaviors (Table 2). Security personnel can help research a patient's criminal background and can stand by when a confrontation with a patient is expected to become explosive. Legal and risk management staff can provide expert advice on the language and timing of communications with patients (for example, responses to threats to intimidate or harm staff). Ethics consultants can help determine the optimal balance between protecting staff and respecting patients' needs for information and care. Their recommendations may depend on the psychiatric consultant's opinion about whether the patient possesses the capacity to make his own decisions or requires involuntary commitment to a hospital (Table 3).

Formalizing these determinations helps ensure that due process occurs before staff reach a decision to terminate a patient's

**Table 3.** Ethical Goals in Terminating the Institution's Relationship With a Difficult Patient

#### Goal

Protect the patient from unfair treatment

Consult with others and act as a team to formulate realistic behavioral expectations

Provide due process with clearly explained expectations and adequate opportunity to comply

Outline alternatives (30-day notice of termination, referrals to three other facilities, emergency care, etc)

Protect the staff from unsustainable burdens

Set limits to prevent abuse and/or threats, disruption of other patients' care, and misuse of resources

Act in the patient's best interest

Use an empathic and dynamic understanding to inform realistic hopes (*v* simply punishing or excluding the patient from care)

Provide the difficult patient the same quality of care that is offered to other patients during the time period in which the difficult patient is asked to modify his/her behavior

Act in the best interest of the institution and future patients

Learn from the experience (understand what responses the patient evokes in staff and correct any staff contributions to the patient's problematic behavior)

care. The process also requires the medical team to articulate and document a valid reason for termination.

## Possible Causes of Difficult Behavior Psychosis

Case 1. A 30-year-old man with testicular cancer undergoing chemotherapy made sexual comments to female nurses and asked one of them for a date. The team requested that he see the hospital psychiatrist, who diagnosed schizoaffective disorder with a propensity to become disorganized and delusional as well as garrulous, intrusive, and sexually inappropriate unless he took antipsychotic medication. The patient showed little insight into his illness, but he agreed to receive injections of depot fluphenazine as a condition of continued treatment in the clinic.

Patients who present with socially odd behaviors that are disturbing to clinicians, although not clearly intrusive or threatening, may prompt clinicians with limited exposure to mental illness to overreact by avoiding, labeling, or unilaterally dismissing the patient.

Case 2. A 60-year-old man with prostate cancer sent his female oncologist several six- to eight-page letters questioning her treatment plan, presenting technical information he had gleaned from the Internet that made only partial sense and discussing his sexual function and feelings of anger and vulnerability in a way that made the oncologist feel frightened and prompted her to send him a letter terminating his care.

Subsequent review by the full team found that the patient's letters were an awkward expression of distress from a man with marked social deficits, possibly as a result of Asperger's syndrome, but that they did not convey a threat toward the oncol-

ogist. In this case, the center's protocol for dealing with threatening behavior had not been followed.

## Sociopathy

Some patients and family members who lack empathy and/or have a history of violence present a credible threat to their providers. In these cases, early involvement of the hospital's legal and security departments is crucial.

Case 3. A 45-year-old woman with a history of severe childhood sexual abuse presented for treatment of locally advanced breast cancer. She initially tolerated treatment and then was forced to stop as a result of a decrease in her cardiac ejection fraction. She began to express great anxiety about tumor progression, said she did not trust her male oncologist's judgment, and presented to clinic several times, demanding immediate attention. Her boy-friend became verbally aggressive, often stood close to nursing staff in a way that felt physically intimidating, and echoed her distrust of the oncologist's medical judgment. He left the oncologist accusatory and threatening messages on his cell phone, despite being asked to stop this behavior, which led the oncologist to seek help from security and hospital administration.

Discussions with legal counsel and hospital security led to a joint decision to ban the patient's boyfriend from the clinic and to require that the patient receive a mental health assessment. The psychiatrist noted that the patient had some symptoms of post-traumatic stress disorder, that she was unable to see her boyfriend's behavior as threatening toward staff because her relationship with him was less abusive than prior relationships, that she depended on him for emotional and financial support, and that she saw him as protecting her from exploitation by the medical system. The boyfriend never expressed any regret for his actions, and the patient ultimately transferred her care to another center.

### Disinhibition

Behavioral disinhibition, expressed as anger, frustration, and sexual/physical/verbal intrusiveness has many potential causes. Neurologic impairment may cause predisposed individuals to become loud, dismissive, profane, and verbally or even physically abusive.

Case 4. A 51-year-old single woman with Huntington's disease presented for a workup of possible polycythemia vera. She refused to be seen in hematology, and after being given an appointment in oncology, she called repeatedly and used profanity to demand an earlier appointment. The oncologist who saw her found breast masses and lymphadenopathy, and recommended a lymph node biopsy. She began to page him and other clinic staff at all hours, with various demands (for example, to be paid to use her own cab company rather than that with which the hospital had a contract). During one visit, she also was loud, demanding and difficult to interrupt, and she pushed her wheelchair into the physician. Her oncologist decided that he would be unable to see her or obtain her cooperation for a biopsy without psychiatric consultation, but she refused.

In this case, the psychiatrist was unable to see the patient but was able to obtain, from a partner hospital from which the woman had been banned from receiving nonemergent care, the information that a psychiatrist and neurologist who had seen her over time had diagnosed borderline personality disorder and progressive emotional dysregulation secondary to mild Huntington's dementia. This information helped the team to encourage her to follow-up on her care with these providers as well as with her primary physician, with whom she retained a working relationship.

Sexual disinhibition is most often seen in male patients who are struggling with impotence and feelings of loss of control. Isolated or sporadic behaviors, such as those resulting from alcohol intoxication, may be contained relatively quickly with feedback and the setting of limits. More serious substance use disorders (such as misuse of prescribed pain medications), can require a team-based approach that includes toxicology screens, limited prescription supplies, and assessment for mental health comorbidities. Repeated behaviors that arise from more complicated psychological vulnerabilities (with or without comorbid substance abuse) also require a comprehensive management strategy.

Case 5. A 58-year-old man with bipolar depression and attention deficit/hyperactivity disorder presented for treatment of recurrent prostate cancer. His depression was in remission, but he had chronic feelings of failure, because his mental illness had prevented him from living up to his father's expectation that he become a lawyer. The patient demonstrated inattentiveness, tardiness, logorrhea, and decreased awareness of how clinicians might perceive his behaviors as inappropriate. On one occasion, he wore a white doctor's coat to an appointment thinking this was humorous, and several times, he was found wandering the hallways well after clinic hours. His female nutritionist felt that his constant discussion of bowel problems had uncomfortable sexual undertones and that he frequently stood too close to her despite her asking him not to. A female receptionist found his increasing attention (including a gift) to be sexually inappropriate and asked to be reassigned to a different location. This array of disinhibited behaviors led his team to request the involvement of the Department of Patient and Family Relations.

After meeting, the multidisciplinary team sent the patient a letter that outlined behavioral expectations for his continued treatment at the hospital and referred him for a psychiatric evaluation. During the next five months, despite a series of laborious and often painful individual and team meetings with the patient, the patient was unable to see how some of his behaviors could have made female staff feel uncomfortable, even if his intentions were benign. He repeatedly voiced feeling that the team's treatment of him was unfair, dismissive, and belittling. However, with constant reinforcement of behavioral expectations, he completed treatment successfully. The staff felt protected and took pride in their professional accomplishment of helping a vulnerable patient to complete a difficult course of treatment.

## **Severe Anxiety**

Individuals with a history of severe generalized anxiety, panic attacks, or childhood trauma may experience overwhelming fear and anger in situations in which they feel at the mercy of authorities they mistrust. Intense, conflicting feelings of anxious patients toward clinicians can lead to repeated calls and time-consuming requests for attention to their concerns.

Case 6. A 56-year-old single, part-time contractor presented for treatment of stable metastatic prostate cancer after being refused additional care at a local cancer center because of his behavior, which included unrelenting questioning of his providers. His history included chronic back pain with ankylosing spondylitis, childhood physical and sexual abuse, longstanding anxiety with panic attacks, and a strong concern that he might not be taken seriously. When he experienced a tearful panic attack during a bone scan and disrupted the technician's schedule, he was asked to see a psychiatric consultant.

Consultation with his local oncologic and mental health providers led to an agreement that he would continue to receive his mental health care at home and see the center's psychiatrist for support whenever he came to the cancer center. In addition, he would limit his calls to a weekly time slot when his nurse practitioner was available. He agreed to and complied with this plan for a period of months and then sought another opinion elsewhere.

## **Personality Disorder**

Maladaptive personality traits can contribute to patient struggles with caretakers in a variety of ways. 8,11 In tertiary outpatient settings, problems caused by mistrustful and controlling individuals are particularly common. For example, when unable to dictate the terms of their care, some patients may threaten to sue or promptly take their complaints to their clinician's supervisor or licensing agency. Their clinicians, who often feel that they have bent over backward to accommodate such patients, can easily feel betrayed, angered, and intimidated. Sometimes, intervention by a hospital-based patient advocate is successful in mediating a resolution of an issue, such as the patient's request to change providers. At other times, the patient's wish to control his or her care leads to continued requests for transfers and/or deviations from standard procedure.

Case 7. A 53-year-old single, disabled woman from a neighboring state with metastatic but stable breast cancer requested repeated changes in oncologists (one oncologist sight unseen because the oncologist was late for their first visit), refused to work with the nurse practitioner on the team, insisted on having scans performed at other hospitals, cancelled multiple appointments, and was disrespectful to receptionists. She left abruptly when her oncologist invited a psychiatrist to join them in discussing her behavior. When the head of the department refused to allow a fourth change of provider without meeting with her to discuss behavioral expectations, she dismissed overtures from the center's Department of Patient and Family Relations, made repeated calls to the office of the center president, reported the institution to the state's Department of Public

Health, and threatened to report the center's psychiatrist to the Board of Registration in Medicine.

Responding effectively to this patient required extensive coordination among her primary clinicians and the center's mental health consultant, Department of Patient and Family Relations, and legal and risk management departments as well as detailed documentation of her behavior and of the center's response to it. Although she refused to accept that the center's behavioral expectations outlined in its letter to her were reasonable and her complaints triggered an official inquiry by the Department of Public Health, these measures demonstrated that the hospital had acted in good faith and with due diligence.

### **Discussion**

We have observed that the ethos of comprehensive cancer centers to extend care and attempt cure "without limits" makes these institutions particularly vulnerable to encouraging unrealistic expectations and accompanying unacceptable behavior of troubled patients and family members. Given that decisions to set helpful limits on this behavior can be agonizing and exhausting for staff who are also attempting to care for other seriously ill patients, multidisciplinary support for primary clinicians is essential. Our experience has been that institutional guidelines for addressing disruptive behavior can remind medical teams to involve psychosocial clinicians early in responding to difficult patients, can provide them with a method and authority by which to set needed behavioral limits sooner rather than later, and can standardize the process of communication among various clinicians and support staff. Mental health consultants can be of particular assistance with more complex situations in understanding the causes of treatment-disrupting

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behavior and in helping the team to set appropriate behavioral expectations (including when considering whether decisions for termination are clinically justified as well as supported by due process). Significant limitations of this approach are that mental health professionals may not be readily available and there may be logistical difficulty of coordinating team meetings in a timely fashion. More systematic attention to this area is needed to clarify how supporting and consulting resources can be optimally deployed.

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#### Authors' Disclosures of Potential Conflicts of Interest

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